

Balancing Risks and Benefits of Deception in Assessing Genetic Screening*

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The Human Genome Project is a massive international research program designed to map the human genome sequence(1). The fundamental purpose of the program is to spur a transition to DNA sequence-based biology and biomedical science(2). In addition to revolutionizing medical diagnostics and therapy, the Human Genome Project will create new challenges in a variety of fields including law, medical ethics, public health, and health services administration(3). The anticipation of these changes does not represent a distant concern. A “working draft” of the entire human sequence is expected by the end of 2001(2).

Against the backdrop of the Human Genome Project, this article critically examines the use of intentional deception to assess (and anticipate) the utilization of genetic screening for alcoholism susceptibility. For some time, the manipulation of study participants by deception has been controversial in experimental social psychology(4). This controversy has emerged in health behavior research as a consequence of the remarkable progress made by the Human Genome Project. Little is known about the public’s interest and utilization of clinical genetic testing(5). In the specific area of *predictive* genetic screening, a deception paradigm (described below) has been found useful for assessing utilization. This paradigm helps estimate utilization when such tools are on the horizon, but not yet available to the consumer. Intentional deception appears to be necessary because “hypothetical testing,”(6, 7) honestly described to research subjects as available “sometime in the future,” generates inflated interest compared to testing described as “currently available”(8, 9).

In an editorial that appeared in the *Journal of American College Health*, “Hard Questions About Research Procedures: The Search for Authenticity”(10), Dr. Richard Keeling objected to the use of deception in a quasi-experimental study conducted by the authors. The report of this investigation appears in the same issue of that publication “Application of a Bogus Testing Procedure to Determine College Students’ Utilization of Genetic Screening for Alcoholism”(11). Interested readers may turn to that article for a full description of the study methods, including the fabricated story concocted to test student interest in genetic screening for alcoholism susceptibility.

Dr. Keeling’s editorial is an example of a conservative, but perhaps increasingly common position

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on human subjects protection that exaggerates risk to study participants and discourages potentially valuable inquiry. The conservative position is based on the following beliefs: 1) deception is inherently harmful; and 2) deception research is not carried out under realistic conditions and therefore is not of value. The authors believe their views are based on an ethic of measured and reflective discourse, instead of a “knee-jerk” response fashioned to serve a particular ideology.

According to Aronson and colleagues (4), when considering the use of deception in research, investigators must weigh the psychological discomfort participants may experience against the value of the study. There is no single set of rules that can be applied to resolve this dilemma, and reasonable professionals will arrive at different judgments in this difficult analysis. To determine college student interest in genetic screening for alcoholism susceptibility, it was reasonable to expose them to what was believed to be modest psychological and social risks. The Institutional Review Board at Kent State University concurred, and with certain stipulations gave approval to conduct the study.

The subjects in this study were deceived about the availability of a genetic screening test. For up to seven days, 181 students thought they could schedule a predictive screening test for alcoholism that does not yet exist. The authors did not believe that this lie harmed the students in any substantial way. In broad-brush comments, Dr. Keeling (10; see page 101 of his editorial) claims that today’s college students are often exploited by society and that any challenge to their “search for authenticity” poses an unacceptable risk to their mental health and/or future social functioning. It seems that this view is not unusual in academia today. Such a position represents “politically correct” discourse that exaggerates the risks of deception in this study and casts a broad net of condemnation over all uses of deception in research. Clearly, humans have been mistreated in research that employed deception (e.g., the Tuskegee Syphilis Study), but distinctions can and should be made in its application.

In this era of heightened concern about compliance with Federal regulations on research involving human subjects, “minimal risks” in behavioral science research have sometimes been subtly redefined as “unacceptable risks.” The authors have no data to support or dispute such speculation, but wonder whether the balancing of

risks and benefits has tilted toward the former in recent years. If so, does this shift represent increased concern for human subjects? An iconoclastic interpretation is that the conservative analysis of risk has been motivated by fears of lawsuits and a desire to protect the university from legal action. In addition, doubts about the quality and usefulness of behavioral science research in general, may be in operation in some quarters which only further discourages full consideration of the potential benefits of such work.

No data were collected in this study to support the claim that the students were not harmed by the deception. However, it should be noted that the empirical literature does not support the view that research using deception is any more harmful than non-deception research (4). One review of the literature concluded that it was rare for participants to feel that they had been harmed by intentional deception (12). Though empirical studies on the effects of deception are few, those that have been conducted generally have found that participants report greater enjoyment from having participated in a deception experiment than in a nondeception experiment (13). This is probably due to deception studies being less boring (4). To address these concerns, in the future, investigators should follow up with participants to determine their reactions to research deceptions.

It is noted that the source of discomfort in deception research is not only learning later that one has been deceived, but equally, if not more important is that the person often learns something painful about themselves or others (14). Again, data were not collected to support this hypothesis, but it is strongly suspected that among those students who were uncomfortable in this study, the primary source of their discomfort was their current drinking behavior. As noted, the sample was over-represented by heavy drinking students. Participation in the study required them to reflect on their own alcohol use as well as that of their family members. Indeed, it was sensed by the authors that some students were uncomfortable while responding to the questionnaire and watching the presentation. In other words, the discomfort that some experienced appeared to occur *before* the debriefing, rather than after it (when they learned they had been deceived). Some students actually appeared amused during the debriefings.

The level of discomfort experienced by

students was probably comparable to being asked to participate in an anonymous self-report survey of alcohol use, and probably no greater than sitting in routine lectures and discussions in health education courses that deal with any number of sensitive issues. The discomfort that some may have experienced was not considered to be detrimental or bad. Good health education "shakes up" students by confronting biased perceptions of risk and challenging existing social norms. It also is consistent with the traditional view of higher education, which is to challenge conventional thinking and behavior and to engage students in debate about controversial issues.

Dr. Keeling (10) also was critical of the contention that the study conditions were "realistic." The authors agree with his observation that if (or when) genetic testing for alcoholism susceptibility becomes available, protocols very likely will require extensive patient counseling before and after the procedure. So by this benchmark, the study's procedure was not realistic. The authors should have been more precise by stating that "our method was more realistic than using a procedure that described screening as a future possibility." However, at the same time, introducing extensive patient counseling into the study procedure would have required us to employ a far greater level of deception. Such a research design would be considered unethical by virtually all professionals and would justify Dr. Keeling's response. This study protocol, however, does not.

As the study was carried out, participants were deceived for no more than seven days. They were debriefed and offered the opportunity to withdraw their data without penalty. In his editorial, Dr. Keeling (10) stated,

. . . Having watched a computer-generated presentation (for 7 minutes) and heard a brief explanation of the study itself, they were then required to state their intentions about being tested immediately. There was little time for them to ponder the issues and submit a formal request to be tested. . . (p. 100).

This description of the study's methods is not accurate. Careful reading of the methods clearly stated that students were told they did *not* have to make a decision immediately after the presentation. A questionnaire item allowed them to respond *I am uncertain about whether or not to be tested* (see p.106 of our article)(11). Further, their participation was always voluntary and invitational. They were able to cease

participation at any time without penalty. Dr. Keeling was accurate in describing that over the next seven days, students were not given counsel or additional information about the test. In this respect, the procedure was not as realistic as future testing probably will be, but neither was it as unrealistic as described by Dr. Keeling in his editorial. It is acknowledged that in the future, people may contemplate the testing decision for extended periods of time, perhaps even many years. Obviously, this study does not address readiness to seek testing over extended time intervals, but it does provide marketing information about what to expect if promotion of genetic screening for alcoholism susceptibility among high-risk drinkers becomes a public health goal.

The preliminary findings from this study suggest that among college students, there may be little enthusiasm for seeking alcoholism screening if (or when) it becomes available. Certainly this issue deserves further investigation. The authors believe the health promotion profession has an obligation and responsibility to conduct research that anticipates and informs the development of sound public health policy. If future public health policy supports genetic testing for alcoholism susceptibility, ethical questions need to be raised by the professions concerned with public health. This study is part of the foundation needed to address these questions.

These debates are important and healthy, but they are not easy. The issues surrounding genetic testing are complex. Billions of dollars are being spent on genome research for the purpose of developing effective technologies to treat and prevent disease. Yet, relatively little attention is being given to the behavioral, social, and health service implications of this technology. There is a need to better understand the utilization of predictive screening for a variety of disorders, including alcoholism. This study should stimulate discussion among health promotion professionals about these aspects of genetic testing.

Bibliography

1. National Human Genome Research Institute. The Human Genome Project. www.nhgri.nih.gov, 2000; April, 14.
2. Collins FS, Patrinos A, Jordan E, Chakravarti A, Gesteland R, et al. New goals for the U.S. Human Genome Project: 1998-2003. *Science* 1998;282:682-689.

3. Khoury MJ and Genetics Work Group. From genes to public health: The applications of genetic technology in disease prevention. *Am J Pub Hlth* 1996;86:1717-1722.
4. Aronson E, Ellsworth PC, Carlsmith JM, Gonzales MH. *Methods of Social Psychological Research* (Second Edition). New York: McGraw-Hill; 1990.
5. Croyle RT, Lerman C. Interest in genetic testing for colon cancer susceptibility: Cognitive and emotional correlates. *Prev Med* 1995;22:284-292.
6. Kessler S, Field T, Worth L, Mosbarger H. Attitudes of persons at risk for Huntington's disease toward predictive testing. *Am J Hum Genet* 1987;26:259-270.
7. Williamson R, Allison MED, Bentley TJ, Lim SMC, Watson E, et al. Community attitudes to cystic fibrosis carrier testing in England: A pilot study. *Prenat Diag* 1989;9:727-734.
8. Craufurd D, Dodge A, Kerzin-Storarr L, Harris R. Uptake of presymptomatic predictive testing for Huntington's disease. *Lancet* 1989;2:603-605.
9. Tambor ES, Bernhardt BA, Chase GA, Fadden RR, Geller G, et al. Offering cystic fibrosis carrier screening to an HMO population: Factors associated with utilization. *Am J Hum Gen* 1994;55:626-637.
10. Keeling RP. Hard questions about research procedures: The search for authenticity. *J Am Coll Health* 1998;47:99-102.
11. Thombs DL, Mahoney CA, Olds, RS. Application of a bogus testing procedure to determine college students' utilization of genetic screening for alcoholism. *J Am Coll Health* 1998;47:103-112.
12. Baumrind D. Research using intentional deception: Ethical issues revisited. *Am Psychol* 1985;40:165-174.
13. Christensen L. Deception in psychological research: When is it justified? *Personality and Social Psychology Bulletin* 1988;14:664-675.
14. Smith SS, Richardson D. Amelioration of deception and harm in psychological research: The importance of debriefing. *Journal of Personality and Social Psychology* 1983;44:1075-1082.